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ABSTRACT

This paper explores how principles of self-determination apply to individuals who are deaf-blind and how it affects families, educational programming, and service delivery. Five underlying principles are identified including: all persons desire self-determination and are capable of achieving it; self-determination is a continuum; and self-determination is a life-span issue. Different cultural interpretations of the concept of self-determination are noted. Practices that foster self-determination are discussed including: (1) opportunities for decision-making and risk-taking; (2) access to the environment through communication; and (3) vocational experiences and employment. Suggestions are offered to serve providers for infusing self-determination concepts into technical assistance services and program planning, including the Individualized Family Service Plan, the Individualized Education Program, and the Individualized Transition Plan. Discussion of curricula focuses on the current development of specific curricula for young adults, family members, and educators. A review of resources notes state deaf-blind projects, information and referral resources, Helen Keller National Center regional representatives, national organizations, and e-mail discussion groups. (Contains 32 references.) (DB)

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Briefing Paper

Self-Determination for Children and Young Adults Who Are Deaf-Blind

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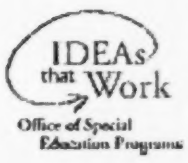

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Introduction

Adolescence is a time of transition for everyone. It is a time when young adults lift their wings, become independent, and take on new responsibilities. By doing so they are allowed to take risks and make choices. This process does not occur just during adolescence, however. Through experience, children of all ages gain skills that enable them to become responsible adults who can advocate for themselves. This path toward self-determination should be the same for children with disabilities. Self-determination is "the ability of individuals to make the choices that allow them to exercise control over their own lives, to achieve goals to which they aspire and to acquire the skills and resources necessary to participate fully and meaningfully in society" (Center on Self-Determination, 1997). It is a combination of behaviors and values that allows people to realize their desires in ways that they choose. People who are self-determined participate actively and responsibly in their own lives. They have supportive relationships, a sense of freedom, and opportunities to take risks.

People with combined vision and hearing loss may have additional physical or cognitive disabilities. Self-determination is an appropriate goal for these individuals as well. With an appropriate level of support, people with significant disabilities can lead self-determined lives. This paper explores how self-determination applies to individuals who are deaf-blind and how it affects families, educational programming, and service delivery.

Understanding Self-Determination

Underlying Principles

Self-determination is a complex concept with multiple definitions and perspectives. There are, however, some consistent characteristics.

All persons desire self-determination and are capable of achieving it. Each of us has an innate drive to satisfy our own needs and lead a life of our choosing. Individuals who are deaf-blind have the same desire.

Self-determination is a continuum. It does not mean having complete control over every aspect of life because no one has total control. Some individuals who are deaf-blind have the ability to exert control in many areas, while others have it in only a few areas. This continuum is representative of variations in personality and skill and the degree of support that is available. Nature, disposition, and the personality of an individual all influence self-determination (Erwin & Brown, 2000). Because children have unique personalities and perspectives on the world, the level at which control is exercised may vary. What may be a comfortable level of self-determining behavior for one person may not be for another. Respecting one's own values and behaving in accord with them are important aspects of self-determination.

Self-determination is a life-span issue. It does not just develop during adolescence. Children of all ages should be encouraged to develop skills that are age-appropriate such as making choices about food, clothes, and free-time activities. As children mature into adults, the areas in which they exert personal control change.

Self-determination results from interaction between the individual and the environment. It does not occur alone or in a vacuum. To become self-determined, one must interact with the environment through observation in order to get information, see how choices affect other people, and make changes and decisions based on feedback from the environment (Abery, 2001).

A Personal Perspective by Jamie McNamara

I can't imagine my life without the concept of self-determination. I have been blessed to have parents, teachers, family members, peers, and professionals who have encouraged me to be self-determined. Back when I was growing up, "self-determination" was not a common word in education, yet the people around me seemed to instinctively know that in order for me to grow I needed to experience many different age-appropriate opportunities. These opportunities were like building blocks that would take me to the next skill level. Once I realized I could do things just as well as the other kids, there was no stopping me! I became an active participant in everyday life both in class and in recreational activities, making my own choices and learning as I went.

I am especially thankful for those who taught me alternate ways to achieve independence despite having a hearing and vision loss. For example, learning to drive is a milestone of independence for teens. I had a wonderful mobility teacher who was brought in at the perfect time while I was struggling with not being able to drive. Instead my instructor empowered me by teaching me how to use public transportation. That experience renewed my confidence.

Even though my parents and family had mixed feelings initially about my taking the buses by myself, they recognized it was important for me to be independent especially for the future. With the skills I acquired, now I can read bus schedules and figure out the transportation systems wherever I go. This was an important skill to acquire because it boosted my level of self-assurance and affected my decision-making related to travel. Self-determination is so important in order for anyone to lead a high quality and satisfying life. For me, life without it would not be as satisfying, that I assure you!

Being self-determined does not mean that a person must be completely self-reliant. In fact, a healthier and more logical approach is to learn to be "interdependent." Kris Schoeller suggests that interdependence is a combination of the connections that we have with others and the support that we receive from the people around us. "Our brain, our spirit, our emotions, our psyche, and our sexuality all function better in social interaction than in isolation" (Schoeller, 1993, p.1).

Cultural Influences

The concept of self-determination may have different cultural interpretations. For example, Latino families may work more closely as a family unit to make decisions regarding a child. One Latino mother stated "Here, in the United States . . . you always ask the child first, and for us it's very important for us as a parent to participate. And so the way they handle those IEP meetings is like the American people, and they're not considering Chinese or Hispanic or any other culture" (Turnbull & Turnbull, 2001, pp. 57-58). Family values and cultural beliefs significantly affect an individual's level of self-determination.

Dr. Brian Abery states, "The opportunity to engage in decision-making, and regulate one's own behaviors within the context of family relationships, provides children the chance to acquire skills and develop belief systems that allow them to exert control over their lives as adults" (2001, p. 4). When a child engages in family discussions and participates in decision-making, he will learn about the cultural beliefs shared by family members.

Practices That Foster Self-Determination

Opportunities for Decision-making and Risk-taking

The world around us gives us feedback regarding the choices we make, whether they are grand or insignificant. Maureen Wall and John Dattilo (1995) stress the importance of establishing environments that are responsive. When children who are disabled make attempts at conversation, choice-making, or any type of independent interaction but do not receive feedback or reinforcement for their attempts, a sense of learned helplessness may develop that leads to inequality between the child and the people in his life. The child learns that his input into the decision-making process is not valid.

> *"Self" involves consideration of who individuals are as people and how they arrived there. . . . "Determination" involves power, taking control, and demanding real choice.*
>
> ***Marca Bristo, National Leadership Summit on Self-Determination and Consumer-Direction and Control (2000)***

According to Abery (2001), there are three main agents that facilitate the development of self-determination: the classroom, the student, and the family. The student is at the center. The school and family must work together to allow the child to experience and share opportunities similar to same-age peers. Often, other people make decisions about and for a person who is deaf-blind. This overstepping is not done maliciously, but it is often a natural response by people who care for and want "what is best" for the individual. Oftentimes adults are afraid to let youth make decisions because of a concern that they may not select the best options (Powers et al., 1996, p. 263). Decisions about daily life are crucial to the child and can be easily influenced by parents or educators. It can be extremely damaging for these decision-making opportunities to be taken away. Robert Perske (1972) believes that one

single-handedly diminishes human dignity by denying an individual his right to choose when it is done in an effort to protect him from risk. Choosing what to wear or what cereal to eat for breakfast may seem insignificant. But, if an individual does not have control over even the simplest of daily tasks and if overruling by someone else occurs regularly over the course of one's life, his self-assurance as a capable decision-maker is diminished.

Parents and educators typically limit opportunities for young adults who are deaf-blind to make choices or take risks. The process of letting go and allowing any young adult to make independent decisions and experience the consequences is difficult. When a child has disabilities, the process may be even more challenging. Throughout the child's life, a parent or guardian may have been the sole "voice," expressing the child's needs in and out of the classroom. Letting go of that role and allowing a child to speak for himself may be difficult.

With the best of intentions professionals, too, may unknowingly discourage independent choice-making (Wall & Dattilo, 1995). Now that children with disabilities are being educated in inclusive educational environments, teachers find themselves increasingly challenged and overwhelmed. Many teachers do not have the skills necessary to appropriately serve children with special needs. Historically, general education teachers were prepared to work with children of "normal intelligence," and special educators were trained to work with children who had "special needs." In the past fifteen years, expectations in the classroom have changed significantly, while many teacher preparatory programs have not. In an inclusive classroom of twenty-five or thirty children, it is difficult for a teacher to meet the individual needs of each and everyone of her students. Therefore, decisions are often made for students who are the most challenged. Students with the highest number of skills and the least significant disabilities are afforded a strikingly higher number of opportunities to make independent decisions (Kishi et al., 1998).

In order to bridge the gap between teachers and students, external supports are sometimes needed. In the United States, every state receives a certain level of federal support intended particularly for children and young adults who are deaf-blind in order to address this barrier. These funds are used, in part, to fund state technical assistance projects, which provide assistance, training, and guidance to teachers and paraeducators.

For young adults who are deaf-blind to transition smoothly from school to work and community environments, specific skills must be acquired. Michael Wehmeyer (1992) suggests that in order to promote self-determination the teaching environment needs to provide classroom control, not overregulation. Skills such as self-regulation and problem-solving should be taught, self-management procedures in the workplace must be encouraged, environments must be structured so that choice-making is supported, and instruction should be organized to provide adequate challenges and appropriate feedback. However, Dr. Abery and colleagues argue that this is only one piece of the equation. In addition to teaching specific skills, they believe it is important to facilitate the development of knowledge that supports self-determination and to ensure that

children acquire attitudes and beliefs that will lead them to use these capacities on a regular basis (Abery, 1994; Abery & Stancliffe, 1996).

Access to the Environment Through Communication

Because of hearing and vision limitations, many teens and young adults who are deaf-blind need support from others to access what is happening in the environment. This kind of support will foster self-determination skills that come naturally to those who can see and hear. Young adults who are deaf-blind also need to witness the steps their peers go through when making decisions. Abery believes that a strong internal locus of control—an inner awareness of the areas one has control over in combination with actual control over one's environment—is essential for individuals who have limited hearing and vision.

Because people who are deaf-blind require alternative modes of communication such as Braille, large print, object symbols, communication boards, or tactile sign language, more time and attention are needed to provide access to the type of information their peers acquire by observing, listening, and talking at home and in other environments. This crucial need for more accessible communication is often overlooked by a majority of people in the individual's life.

> ***Supporting people with disabilities includes supporting them to be causal agents in their own lives and providing a supportive environment for the risks they choose to take.***
>
> ***University Affiliated Program of Rhode Island (2001)***

Family members, teachers, and other people involved with children who are deaf-blind should address the need for accessible communication. Also, service providers who work as communication facilitators should provide this access. These service providers include interpreters, interveners, and support service providers (Morgan, 2001). Their roles vary depending upon the needs of the individuals they serve, but they share a common purpose—to facilitate communication and provide access to auditory and visual information that, in turn, empowers people who are deaf-blind. They provide information about and equal access to the environment, which enables each person to make more independent decisions. This encourages self-determination.

The increasing awareness of the need for interpreters, interveners, and support service providers is exciting and crucial for the success of students with deaf-blindness. Currently, however, there is a lack of standardized definitions and prerequisite training for these positions. These professionals have opportunities to enhance or diminish the number of occasions during which an individual who is deaf-blind can exert personal choice. John McInnes points out, when writing about the responsibilities of an intervener, that intervention is "a process, the purpose of which is to enable the deafblind person to establish and maintain maximum control over his or her environment at a level appropriate to physical ability and level of functioning" (1999, p. 76). If these professionals remember that their role is to facilitate an individual's expression of wants and desires, then self-determination is fostered.

Vocational Experiences and Employment

Early community-based vocational experiences are important for young adults who are deaf-blind. These experiences make it possible for them to acquire the skills, knowledge, attitudes, and beliefs that will help them to prosper vocationally. According to findings presented in *The National Transition Follow-Up Study of Youth Identified as Deafblind: Parent Perspectives,* however, few students who are deaf-blind receive adequate vocational training and very few ultimately become employed (Petroff, 1999). This study surveyed the parents of 97 young adults who left the educational system in 1998. Only 12 percent received community-based vocational instruction during their school years. Eight percent had been involved in competitive or supported employment experiences. Twenty-five percent were included in simulated or sheltered work experiences. Fifty-five percent did not receive any vocational programming.

Self-Determination Training at Work

In August 2000, The National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind (NTAC), in conjunction with the Institute on Community Integration, hosted a teen seminar entitled "Self-Determination: Creating a Path to the Future" at the American Association of the Deaf-Blind (AADB) conference in Columbus, Ohio. A training program was developed that consisted of thirteen teams of individuals from across the country. Each team consisted of a young adult who is deaf-blind, a mentor who is deaf-blind, and a state organization representative. The teams reflected the diversity of this population. Participants learned about self-determination and some of its key factors. Discussions took place about the skills, knowledge, and resources necessary to become a self-determined individual. Participants also learned about the importance of dreaming for the future and the importance of having supportive people involved in the process. Each team devised a plan of action that listed self-directed goals for the team's young adult and identified steps to achieve those goals. Throughout the following year, team members maintained contact with each other and used the action plan as a roadmap to achieving and supporting self-determination.

Here is an example of one student's dream.

Mansur Ferrell, Georgia

Dream: In the future I would like to . . . *work for the NFL or a game company.*

Vision: In order for me to reach my dream I must . . . *attend technical school.*

Goals: The steps I must take in order to realize my vision are . . . *take the SAT test, develop good study skills, maintain good grades, graduate from high school, meet with a Disability Services Counselor, set up a system to ask for assistance, and graduate from technical school.*

An astonishing 82 percent were unemployed two years after leaving school. This is disturbing when compared to unemployment rates of the general population (5 percent at the time of the survey). Thirty-two percent of the parents surveyed did not believe that their child possessed the capability to work, or to work in potentially challenging environments. These results raise the question of whether teaching self-advocacy and

self-determination skills at a younger age would reinforce vocational goal setting and give these young adults a better chance to achieve their goals.

Implications for Service Providers

Infusing Self-Determination Concepts into Technical Assistance Services

Technical assistance providers can help professionals, family members, and peers learn to infuse the concept of self-determination into their daily interactions with individuals who are deaf-blind. Information about self-determination can be included during many types of technical assistance activities, including training programs, meetings with professionals or parents, and when providing informational materials and resources. Any interaction may provide an opportunity to discuss self-determination. For example, the importance of choice-making could be included as part of a presentation on communication. Encouraging parents to support their child to lead his own IEP meeting and inviting a mentor who is deaf-blind to attend the meeting can be included as part of educational program planning.

Because opinions about self-determination vary considerably, it is important for service providers to know their audience and understand their prior knowledge of self-determination when infusing self-determination concepts into technical assistance services. Questions to ask:

- How do the participants define self-determination?
- Is the concept new to them?
- How do a family's cultural beliefs impact their understanding of self-determination?

In order for a team to work well together and with the desires of the child in mind, it is important that all participants understand each other's points of view.

It is also important to determine the intended outcomes of the technical assistance activity. Possible outcomes include the following:

- To raise awareness of the topic of self-determination.
- To give the participants suggestions about encouraging self-determination for the children and young adults in their lives.
- To develop an action plan for a particular individual.

Program Planning

With the reauthorization of the Individuals with Disabilities Education Act (IDEA) in 1997, increased emphasis was given to identifying individual preferences, particularly during the development of Individualized Education Programs (IEPs) and Individualized Transition Plans (ITPs). The law states that the student must be actively involved in the planning and decision-making process. The intention is to identify the student's preferences, create an individualized plan of service, and realize the student's

goals. This student-driven planning process will occur if students are encouraged to identify and share their dreams. Individuals cannot make independent choices if opportunities to develop self-determining behaviors are not available.

Individualized Family Service Plan (IFSP)

An IFSP is the document developed by families and service providers to guide the early intervention process for young children with disabilities (birth to age three) and their families. It outlines the outcomes and interventions that will maximize a child's development, including skills and behaviors that promote self-determination, regardless of the severity of the disability.

The IFSP is based on an assessment of the child and family in natural environments, including everyday routines and activities. Self-determination skills are naturally part of this assessment. During the assessment process, it is important to be aware that "how families and individuals view self-determination and work together to express it will be based on their culture and values" (Alliance for Self-Determination, 2001). The first step in the IFSP process is to assess the child's preferences and choices in his day-to-day life. This can be a natural opportunity to identify opportunities to promote the development of skills that lead to self-determination. In *Research to Real Life: Innovations in Deaf-Blindness*, Deborah Chen, a professor in the Department of Special Education at California State University at Northridge, suggests that determination of a child's needs may be most effective when information is obtained by observation. "For many parents it involves slowing down, waiting for the child to process information, have a reaction or express a need. By doing this, parents are able to discover what the child likes and dislikes" (Leslie, 2001, p. 2). Giving a child opportunities to express likes and dislikes and providing positive responses is a natural first step to promoting self-advocacy.

The IFSP helps families and service providers to develop partnerships that create, utilize, and support opportunities for children to develop various skills in their natural environments in order to enhance the lifelong quest for self-determination. "The foundations for self-determination are laid in the earliest years. Therefore, families should be made aware from the earliest years of ways to facilitate the self-determination of their children with disabilities" (Alliance for Self-Determination, 2001).

Individualized Education Program (IEP)

The Individualized Education Program (IEP) team, which consists of the student, family members, educators, and related service providers, gathers to determine the goals and objectives that are to be implemented for an individual with disabilities for a given academic year. Historically, these meetings have been scholastically driven, facilitated by a representative of the school system, and have often begun with a written document of predetermined goals. This approach did not allow for student or parent involvement in the process.

With the shift from system- to student-driven programming, methods and tools have been created to assess an individual student's preferences. Once the individual's preferences are noted, they are then translated into action-oriented objectives that assist

parents, educators, and service providers to meet the student's educational and developmental needs.

A variety of tools are available to assist with curriculum planning including methods of personal futures planning and mapping (Mount & Zwernik,1989; Carr, 1992-1993) and the publications *Choosing Outcomes and Accommodations for Children (COACH): A Guide to Educational Planning for Students with Disabilities* (Giangreco, Cloninger, & Iverson, 1998) and *Guidelines for Making Decisions about I. E. P. Services* (Giangreco, 2001). These methods take a holistic view of students who are deaf-blind and include family members and loved ones in the process. With the use of these tools, families have reported increased satisfaction with their children's educational programming. No matter how these preferences are identified, it is imperative that young adults be encouraged to dream for the future.

One Family's Experience

From the age of seventeen, Andrew Prouty was the lead facilitator of his IEP meetings. He planned them with his parents at home and with his teachers during class time. During meetings he followed an agenda and included all members of the team. Because of his presence and his critical role within the team, IEP team members were able to observe Andrew's strengths, his mode of communication, his style of interaction, and his knowledge of his own wants and desires. The team also ensured that Andrew covered each of the transition areas on the IEP. They worked collaboratively and were encouraged to develop clear, realistic goals driven by Andrew's preferences. His parents were also able to express their family's desires for his educational programming.

In order for a student's dreams to be realized, his preferences and desires must be the driving force behind the IEP team. Encouraging the student to be the primary leader of this team is one way to do this. If the student is present and given an opportunity to facilitate his own IEP meeting, he can become empowered and the IEP team may find it easier to develop collaborative goals that are congruent with the student's personal values. This collaborative effort encourages the development of self-esteem and self-realization, both factors that foster skills necessary for self-determination.

As an individual grows and changes, his wants and desires and level of personal control may change. IEP and Individualized Transition Plan (ITP) goals should also change to reflect this. The IEP team, including the student and family members, should work together on a continual basis to ensure that the goals identified for the student reflect the child's current desires. Educators should realize that reaching a goal is an ongoing task. The process is never finished. There is always more to be done (Kansas State Department of Education, 2001, p. 7).

Individualized Transition Plan (ITP)

Transition planning is the process that prepares a young adult for the transition from school to work. Traditionally, a young adult either graduates or ages out of the educational system and enters the world of work or postsecondary education. In order to make this shift a smooth and coordinated process, it is crucial to have a transdisciplinary team involved in the planning so that all areas of the individual's life are considered. As

with the IEP team, this group will create a legal document, an Individualized Transition Plan (ITP) that details goals and outcomes to meet the student's and family's desires.

Research indicates that there is a significant disparity in both educational and vocational outcomes between students with disabilities and those without disabilities. There is an even greater difference for students with combined auditory and visual impairments. Levels of unemployment and underemployment for these students far exceed the average for students with disabilities in general (Petroff, 1999). These results are influenced by various factors including inadequate vocational training (Griffin and Wehman, 1996), delayed or lack of transition planning (Petroff, 1999), and poor student and family involvement in program planning.

TAKE CHARGE for the Future, a comprehensive transition-planning model (Powers et al.,1998), is one tool that can be used to address this need to better prepare young adults. It places the student at the center of the transition process while incorporating pertinent information from all areas of the individual's life: home, school, and community. It also assumes that the student is the person primarily responsible for developing the plan, which includes choice-making, goal setting, and development of a systematic plan of action to achieve goals.

As with IEP development, it is imperative to encourage student participation, use tools to identify student preferences, and involve the family in the planning process. In doing so, the team learns the desires of the student and is able to assist in the development and implementation of an educational program that meets the needs of the student who is deaf-blind. As the transition process progresses, activities listed on the ITP should be reviewed, revised, or terminated by the team (Kansas State Department of Education, 2001).

Curricula

A variety of curricula have been developed that teach self-determination skills to individuals with disabilities (Field, et al., 1998; Wehmeyer, Agran & Hughes, 1998; Powers et al., 1998). Many focus on the crucial skills of goal setting and goal attainment. Other topics include decision-making, person-centered planning, employment, education, community involvement, housing, and daily living skills. Only a few curricula focus on problem solving, self-monitoring, or self-instruction skills, and these are important needs to address. What must be considered are the areas of control a student currently has versus the areas the student would like to have (Abery, 2001). Students with disabilities face adversity on a daily basis and confront many environmental barriers. In order to overcome these obstacles, they need tools that allow them to identify the dilemma at hand, locate helpful resources, and redirect and refocus current goals.

Most curricula on self-determination do not consider the unique needs of individuals who have a combined vision and hearing loss. There are specific curricula designed for people who are deaf that address some of the barriers to communication faced by those who are deaf-blind, but they do not address the additional barriers associated with vision loss and its impact on independence and mobility.

Dr. Brian Abery and colleagues at the University of Minnesota Institute on Community Integration are currently developing a set of curricula specifically designed for individuals who are deaf-blind. The development team began by trying to define and clarify the meaning of self-determination for students with combined vision and hearing loss and to identify the necessary components that lead to the development of self-determination skills. This outcome was achieved through a process that consisted of focus groups of young adults, parents who have a child with deaf-blindness, and professionals in the field.

As a result of this process, the team learned that there are five domains or topical areas that affect how a person may be able to exercise self-determination. These are skills, knowledge, attitudes and beliefs, environmental barriers, and environmental resources. All of these represent the variables that influence the life-long process of self-determination.

Three curricula will be developed. The first, *Self-Determination for Youth Who are Deafblind: An Individual Skills Curriculum* (Abery, in press), is for young adults and is currently being piloted in areas around the country. A second curriculum will be developed for family members, and a third, for educators.

Resources

There are many resources available for children and young adults who are deaf-blind, for their families, and for professionals. Having access to information about deaf-blindness will empower the child or young adult who is deaf-blind and support his self-determination.

State Deaf-Blind Projects. Federal funds have been allocated to each state throughout the United States to meet the educational and developmental needs of children and young adults who are deaf-blind. Individuals who are deaf-blind, families, educators, and service providers can all access this support (e.g., training, information, or advocacy) from their state deaf-blind projects. To obtain contact information for a specific state deaf-blind project, contact DB-LINK, The National Information Clearinghouse on Children Who Are Deaf-Blind (see contact information below).

Information and Referrals. DB-LINK is the national clearinghouse for information on deaf-blindness. It is federally supported and provides literature and materials on many topics associated with deaf-blindness free of charge.

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Helen Keller National Center Regional Representatives. Helen Keller National Center (HKNC), a federally funded national training center for youth and adults who are deaf-blind, has ten regional representatives throughout the country. They serve as resources within their region by providing referrals to mentors and training opportunities and by acting as deaf-blind specialists.

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National Organizations. There are two national organizations that were established for and by people who are deaf-blind or their families. One is the National Family Association for Deaf-Blind (NFADB). This organization is run by parents of children who are deaf-blind and was created for the purpose of sharing information and resources and developing a national network of support. The American Association of the Deaf-Blind (AADB) is run by and for youth and adults who are deaf-blind. It has an established administrative board and regional representatives, provides a national membership directory, and publishes a quarterly magazine.

National Family Association for Deaf-Blind (NFADB)
(800) 255-0411, ext. 275
111 Middle Neck Road
Sands Point, NY 11050
nfadb@aol.com

American Association of the Deaf-Blind (AADB)
(301) 588-6545 (TTY)
(301) 588-8705 (FAX)
814 Thayer Ave. Suite 302
Silver Spring, MD 20910-4500
aadb@erols.com
http://www.tr.wou.edu/dblink/aadb.htm

E-mail Discussion Groups. Major advances in technology over the past decade have opened doors to information and resources that have traditionally been closed to people with disabilities. With the growth and expansion of the Internet, individuals who are deaf-blind now have access to the same information as their hearing-sighted peers. A number of e-mail discussion groups have been created that address topics related to deaf-blindness. These have been created for adolescents who are deaf-blind, adults who are deaf-blind, families, interpreters, support service providers, and educators and other professionals. Contact DB-LINK for a list of e-mail discussion groups.

Summary

Children who are deaf-blind have the same needs and desires as their hearing-sighted peers, but they may not be able to naturally attain the necessary skills to become self-determined adults. In order for self-determination to develop, specific attention must be given to the following: skill development (communication, independent living, self-advocacy), knowledge (resources, self-knowledge, general understanding of the environment), attitudes and beliefs (self-esteem, positive outlook, level of control), barriers (lack of accommodations and services, communication barriers, mobility limitations) and resources (education, technology, and social-emotional supports) (Abery, 2001). Individuals who are deaf-blind must be exposed to experiences similar to their nondisabled peers and given opportunities to make independent decisions, experience risk-taking, and dream for the future.

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